MND Association briefing: social care reform proposals in England

April 2022

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1. Overview

This briefing summarises the Association's views on the Government's proposals for social care reforms in England, as well recommending wider principles for social care reforms.

2. Context: MND and Social Care

Motor neurone disease (MND) is a rapidly progressing neurological condition which affects an individual's ability to walk, talk, eat, breathe, and move. Social care is therefore a vital source of support for many people living with MND, their families and those providing unpaid care for loved ones. Good social care can help people living with MND to prolong independence and maintain wellbeing, dignity and quality of life as the disease progresses. However, our 2019 Improving MND Care Survey found that only 26% of people living with MND said they received social care.[1] As an organisation we are increasingly hearing how the system fails to meet the needs of people living with MND who require care and support.

The MND Association believes that social care reform is long overdue, with the situation only worsening since the beginning of the COVID-19 pandemic. The Care and Support Alliance (CSA)[2], of which the Association is a member, has found that since the Prime Minister promised to "fix social care, once and for all" almost two years ago, two million requests for formal care and support from adults aged over 18 have been turned down by their local council.[3] And a survey by the Association of Directors of Adult Social Services (ADASS) found that approximately 400,000 people were waiting for an assessment of their needs or service, and 1.5 million hours of commissioned home care could not be given between August and October 2021 because of a shortage of care workers.[4]

These stark findings are being reflected in the experiences of people living with MND, with our staff reporting that difficulty in getting care packages for people living with MND is more

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[1] MND Association, Improving MND Care Survey, 2019. Access via: https://www.mndassociation.org/improving-mnd-care-survey-2019/
[2] The Care and Support Alliance website can be accessed here: http://careandsupportalliance.com/
[3] Based on Age UK analysis for the CSA of NHS Digital data, June 2021. Access via: https://www.ageuk.org.uk/latest-press/articles/2021/since-the-pm-promised-to-fix-social-care-2-million-requests-for-formal-care-services-have-been-rejected/
[4] ADASS, November 2021. Access via: https://www.adass.org.uk/snap-survey-nov21-rapidly-deteriorating-social-services

widespread than ever.[5] People living with MND are facing a lack of availability of appropriate care packages caused by a lack of trained staff, a limited number of providers, and agencies being reluctant to take on complex care packages. As a result, we are finding that some people with MND are left stuck in hospital, going into nursing care prematurely, or that the burden of care is being left on family and unpaid carers.

We believe this situation is unacceptable and the Government must urgently address this crisis in social care by:

- providing the immediate short-term funding needed to better enable the social care system to cope with current pressures
- delivering comprehensive reforms to put the system on a sustainable footing over the long term and drastically improve the availability and quality of care.

Our views on this are set out below.

3. Social Care charging reform proposals

Cap on care costs

In August 2021, the Government announced plans to introduce a lifetime cost cap on social care costs in England of £86,000. Those with over £100,000 in assets will be required to fully fund their care towards this cap, those with assets between £20,000 and £100,000 can receive means-tested support from their Local Authority, and those with assets below £20,000 will not have to pay care costs from their assets at all. These proposals are underpinned by a 1.25% increase in National Insurance contributions from both workers and employers, which is projected to raise £36 billion over the next three years.

We initially welcomed this as a long overdue step to ensure people do not face astronomical care costs, make the means test more generous and protect those with reduced or without means or assets.

However, in November 2021 the Government updated its proposals, making the social care cap less generous to people with low to moderate levels of wealth by specifying that means-tested contributions from their Local Authority will not count towards the cap. The Association believes this proposal will leave people living with MND with low to moderate wealth still exposed to catastrophic care costs. We are concerned that this will have a particularly unfair impact on people living with MND who are of working age and their families, who are more likely to require means tested support.

While the Government's proposals are still a marginal improvement for those with low to moderate assets compared to the current cap-less system, we believe they negatively counter intentions to make the system fairer by effectively undoing the purpose of the means test. The current proposals do not ensure that those with fewer financial resources make a smaller contribution towards their care costs than those with more. Instead, the implication seems to be that people with lower assets have to pay the same amount if they require care for long enough, will take longer to reach the cap and will end up spending a greater proportion of their assets doing so.

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[5] Based on feedback given by MND Association Senior Delivery Managers, December 2021.

Recommendation: We recommend those receiving means tested support under Government proposals have both their personal and local authority contributions count towards the cost cap.

Zero cap for younger working age adults

Whilst we prefer for a cap to be in place than the current cap-less system, we still believe the proposals leave younger working age adults with MND and their families significantly more disadvantaged. This is because they cannot be reasonably expected to have built up sufficient assets before care needs develop, and their familial circumstances may make financing care costs even more difficult. In Sir Andrew Dilnot's report on the funding of care and support it was proposed that:

> *"Anyone developing an eligible need up to the age of 40 should also face a zero cap, as we do not think that people younger than 40 can, in general, realistically be expected to have planned for having a care and support need, nor will they have accumulated significant assets."*[6]

We believe a zero cap as recommended by Dilnot would help mitigate the risk of catastrophic care costs for younger working age adults living with MND who have had the least opportunity to save and build assets to shoulder them.

Recommendation: We recommend a zero cap be introduced for younger working-age adults who develop social care needs.

Tapered cap up to retirement age

Similarly, we also support the proposal of a tapered cap advised by the Dilnot Commission for those with eligible needs after the age of 40, which increases with every decade up to retirement age when the full cap would apply. We see this as a means of offering some protection to a broader section of working-age adults who have had less opportunity to build savings and assets. It would also alleviate concerns of a 'cliff-edge' should someone be diagnosed with MND after the age of 40.

Recommendation: We recommend a tapered cap be introduced for older working aged adults up to retirement age.

4. Health and Care Bill

The Association is following the passage of the Health and Care Bill through Parliament and we support amendments in relation to our recommendations on social care charging policy. We also support the views of the Care and Support Alliance, and endorse the joint briefing on working-age issues produced by charities that work with and support working age adults.[7]

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[6] Fairer Care Funding: The Report of the Commission on Funding of Care and Support. July 2011.

[7] The Association is working as part of a group of charities that work with and support adults under the age of 65, including MS Society, Leonard Cheshire Disability, Mencap, Sense, National Autistic Society, Epilepsy Action, Disability Rights UK, Inclusion London and the Neurological Alliance. Please contact us to find out more about the work of this group and receive a dedicated joint briefing on social care reform from a working-age adult perspective.

Recommendation: We urge parliamentarians to vote in favour of amendments to the Health and Care Bill in relation to any of the following:

- **Enabling Local Authority contributions to count towards the metering of the care cap,**
- **Creating a zero cap for working age disabled adults under the age of 40,**
- **Creating a tapered cap for working age disabled adults between the age of 40 and retirement age.**

5. Social Care White Paper

Following proposals on social care charging reform, in December 2021 the Government produced a White Paper outlining wider areas for reform. In our view, the White Paper contains some positive elements including its primary ambitions on choice, control and support for people to live independent lives; access to personalised, high-quality care and support; and fairness and accessibility. However, we believe it also leaves major questions unanswered and we are concerned that it is not backed by enough funding to deliver these ambitions.

Housing

We are pleased to see a clear recognition that safe and accessible housing is essential to maintaining good health and wellbeing, and we welcome the new funding to support closer integration approach across health, social care and housing services. We particularly welcome the government's plans to introduce higher maximum grants for home adaptations and review the disabled facilities grant means test, as we called for in our #ActToAdapt campaign. This has the potential to support more people living with MND to remain in their own home by expanding access to necessary home adaptations.

Recommendation: We recommend that officials working on the Government's White Paper proposals read the Association's 2019 Act to Adapt report[8] and work with us to deliver the recommendations that will ensure future proposals will meet the needs of people living with MND.

Unpaid Carers

While the inclusion of ambitions to support carers more effectively within the White Paper is welcome, it is not underpinned by a strategy or significant funding. Rather than funding small pilot projects, the Government should ensure that all carers across the country receive the support and respite that they deserve. In 2021 the Association engaged with unpaid carers of people living with MND and we will publish a report on our findings in 2022. Once published, we will share this report and its recommendations with officials working on the White Paper.

Workforce

The White Paper's workforce strategy fails to properly address the issue of low pay. Without additional support to address levels of pay in the sector, the ongoing shortage of care staff is likely to continue. The pace of change in this area is also of concern, as there is a real and

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[8] Access via: https://www.mndassociation.org/app/uploads/2019/09/Act-to-Adapt-Full-report.pdf

immediate issue that many care workers are not appropriately trained to meet more complex needs as a result of MND, affecting the availability and quality of care in the here and now.

The Association's full position statement on the White Paper can be found on our website.[9]

6. Principles for social care system reform

Beyond specific proposals made by the Government as part of the Health and Care Bill or the White Paper, we believe there are a number of principles that should be followed in order to ensure reform works for people living with and affected by MND. We believe comprehensive social care reform must address the following issues:

- **Social care reform must deliver a funding settlement that is fair, meets the needs of all service users, and is sustainable over the long term**. Reform should not focus solely on narrow issues such as preventing the sale of homes to fund care costs but should deliver a broad-based solution that meets the needs of the whole population.
- **Reform must work for working-age adults as well as older people.** Over 50% of current social care spending goes towards supporting people of working age living with disability or long-term health conditions, yet they are often overlooked in debates around social care reform. Any proposed reform must address the needs of working age social care recipients.
- **Social care reform must address workforce issues,** including ensuring that social care workers receive the pay and conditions they deserve.
- **Social care reform must deliver improvements to care across all settings**, including residential care and home care services, and consider how social care and health services can work together to support people more effectively.
- **A reformed social care system must better meet the needs of unpaid carers**, including improved access to respite care and carers support services.
- **Social care reform should expand eligibility for support.** It is essential that reform does not seek to save money by reducing the number of people eligible to access care and support. Eligibility levels should be set at a moderate level of need, to enable people to access preventative care and community support.

As a member organisation of the Care and Support Alliance, we also endorse the following principles that should underpin social care reform:

1. The cost of care is pooled on a compulsory whole (adult) population basis, funded through taxation.
2. Care is free at the point of use.
3. There is an independent, standardised national eligibility threshold and assessment process for social care, to prevent rationing.
4. Eligibility is set at a 'moderate' level to enable those in need of community and preventative support to access it and to encourage more focus on prevention.

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[9] Access via: https://www.mndassociation.org/our-response-to-the-social-care-white-paper/

5. The care and support needs of working age disabled adults and older people are both addressed.
6. There is increased support for unpaid carers through more breaks and better core support, including helping carers to juggle work and care, and increased Carer's Allowance and other carers' benefits.
7. There is a new deal for care staff, beginning with an immediate pay rise and including an agreement to move to parity with the NHS for the same roles, by a set date; a revised career structure; better training and development opportunities; and registration.
8. Social care must have parity of esteem with the NHS and reform needs to ensure smooth working between social care services and other agencies, including the NHS and housing.

We also support principles for reform as set out by organisations, including the Association, for people who are of working age:[10]

1. Flexibility, consistency and continuity of care around people's lives and needs. That means care workers arriving at consistent and reasonable times e.g. in the morning to support someone to get dressed and ready for work on time, or in the evening so it doesn't infringe on their right to a family life by forcing them to go to bed at an unreasonable time.
2. Availability of age- and need-appropriate care settings so younger adults aren't forced to be in a care home designed around the needs of older people with dementia, for example.
3. Enable personalisation of care through personal budgets and direct payments (DPs). People can't benefit fully from DPs if there aren't the support services locally to help them manage the responsibilities of being an employer and managing a budget on an ongoing basis.
4. Access to specialist support for complex needs with care providers equipped and trained to meet the needs of people with complex conditions. Anything less than this substantially limits choice and often leads to unpaid carers, family or friends taking on more caring responsibilities.
5. Care must be affordable. This must take into account the additional costs related to having a disability and the fact working-age disabled adults have had less opportunity to save for their care.

7. About MND and the MND Association

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound, feeling etc.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- Over 80% of people with MND will have communication difficulties, including for some, a complete loss of voice.

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[10] The Association is working as part of a group of charities that work with and support adults under the age of 65, including MS Society, Leonard Cheshire Disability, Mencap, Sense, National Autistic Society, Epilepsy Action, Disability Rights UK, Inclusion London and the Neurological Alliance. Please contact us to find out more about the work of this group and receive a dedicated joint briefing on social care reform from a working-age adult perspective.

- It affects people from all communities.
- Around 35% of people with MND experience mild cognitive change, in other words, changes in thinking and behaviour. A further 15% of people show signs of frontotemporal dementia which results in more pronounced behavioural change.
- It kills a third of people within a year and more than half within two years of diagnosis.
- A person’s lifetime risk of developing MND is around 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- It affects up to 5,000 adults in the UK at any one time.
- It kills six people per day in the UK, this is just under 2,200 per year
- It has no cure.

The Motor Neurone Disease Association is the only national charity in England, Wales and Northern Ireland focused on improving care, research and campaigning. We have over 9,000 members forming a powerful network that provides information and support for people with MND, their families and carers. We fund and promote research that leads to new understanding and treatments and brings us closer to a cure. We campaign and raise awareness so the needs of people with MND are recognised and addressed by wider society.

8. **Contact:** For further information please contact Daniel Vincent, Senior Policy Adviser daniel.vincent@mndassociation.org